

NATIONAL ACADEMY OF SCIENCES

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Dear Dan:

Thank you for your note of July 5. I do have a copy of my text which needs a little touching up, but I would be willing to have it considered for publication if there is a symposium summary to be published.

I wanted to say a few words about your second paragraph, in which you approach the question of creating an international coordinating committee. This action puzzles me immensely, because it seems to indicate a complete ignorance of the fact that such a body already exists in the form of HUGO. One of the major subcommittees and activities of HUGO deals with ethical, legal and social issues. This subcommittee is chaired by Victor McKusick. He also has chaired an Academy committee dealing with forensic use of DNA technologies. As I mentioned and as we discussed in my office, conferences on ethics of human genome research seem to constitute a growth industry. Because of the number of such conferences HUGO has not organized ethics conferences of its own. In addition, I rather incline toward national or regional task forces on very specific issues, rather than the global approach envisioned in your paragraph. For example, one reaction that came back to me from a British participant was that the Bethesda conference was "a typical example of American arrogance." This reaction apparently related to the emphasis on genetic diagnoses and health insurance, a peculiarly American issue, and some immigration issues, neither of which were discussed when I was personally in the audience. But I think the signal is that we should deal with our own issues and let other regions deal with theirs since many of the matters are so dependent on regional or national ethnic and cultural overtones.

Finally, as Bob Cook-Deegan may have reported to you earlier, I had major reservations about a conference on ethics in which the Soviets played such a prominent role. As it turned out, since the KGB presentation did not come off, the issue was not a major one. I have however read the Frolov and Yudin book entitled *The Ethics of Science: Issues and Controversies*, and it

is pretty heavily laced with Marxist-Leninist doctrine. Perhaps that was obligatory, and perhaps the book would be slanted differently if written today. Nevertheless, I think we should go slowly in assuming that people who are a product of seventy years of such culture suddenly acquire ethical viewpoints that are congenial with those of the western tradition.

I was impressively reminded of the gulf that remains during a recent visit to Moscow when a colleague and I had lunch with a Soviet pediatric surgeon, who discussed the difficulty of obtaining fresh hearts and livers for transplantation in children under age 5. He contrasted the difficulty with that of obtaining kidneys which can be shipped for a number of hours. There is no brain death law in the Soviet Union, at least not applying to children under age 5. What the Soviets have done is to form committees that rule on the acceptability of "using" severely handicapped children who "cannot contribute to society" or "that society does not need" as donors. Apparently such children are being sacrificed to provide hearts or livers for other children. I pointed out that this would be totally unacceptable in the United States. The surgeon then reiterated that they did not have a brain death law, hence no other solution. My colleague later confirmed this practice in two other discussions, including one with Boris Yudin himself.

I think this example illustrates my point, and I rest my case.

Thank you again for your letter.

Sincerely,



James B. Wyngaarden
Foreign Secretary